

169 - ACTIVITIES OF THE DAILY LIFE OF A CHILD WITH CEREBRAL PARALYSIS IN THE FAMILY, SPECIAL SCHOOL AND REGULAR SCHOOL CONTEXTS (CASE REPORT)

CAROLINE EVELYN SOMMERFELD; MARCUS VINÍCIUS MARQUES DE MOARES; THAÍS SILVA BELTRAME
Universidade do Estado de Santa Catarina (UDESC), Florianópolis - SC / Brasil
fisioespecial@yahoo.com.br

INTRODUCTION

Nowadays came across development theories that center your focus of attention well besides the discussion nature/nurture. During life course human being carries with himself inherited characteristics and another acquired current of the context of life, the individual is not only influenced, but also a transformer of his context. In Krebs (1995) it identified the theories of Gardner, Samples and Stenberg that discuss about the multiple intelligence modalities; the theory of Riegel; the theory of personality in development of L'Abates; the theory of Valsiner; and the theory of the ecologic of the human development of Bronfenbrenner as tendency of new approaches.

A lot of researches indicate that the environmental events are capable to modify the child's evolution substantially, during the first years of life. Bronfenbrenner (1996) show us that the environmental events are capable to modify the individual's evolution substantially, mainly in the first years of life, because the growth and the child's development usually increase his independence in the several places that he frequents, where it creates he bows with the community. For Gallahue and Ozmun (2001), the maturity of the motor development is associated to hereditary characteristics, to the environment in that the child lives and his activities in his daily life, and the junction of those three factors that determines the amount and the extension of the acquisition of the motor abilities that are defined as the development of the motor control, represented by the precision and accuracy of the act of fundamental movements until an improve that turns the independent and agile child to accomplish his activities.

In the children with specific needs, for instance, with cerebral paralysis, the child should be noticed as an interactive that needs to live situations in that he will be able to acquire new abilities, as those in that he has autonomy to live the abilities acquired. Lopes (2002) tells that the child that presents some type of specific need is a special child. Special in the family living, because he usually needs larger attention, care and, a lot of times, help by the parents and family for accomplishment of his activities of daily life. Special of the medical point of view, because there is need of a multiprofessional team to accomplish with his treatment success. There are several professionals involved specialists, for instance, Doctor Pediatric, Physiotherapist, Psychologist, occupational Therapist, Educator, among other professionals. This team should be harmonic and to work together to provide to the special child best quality of possible life, so that she gets to develops according to his maximum potential.

The cerebral paralysis is defined by Bobath (1989) as a chronic encefalopatologia, not progressive, that happens due to a lesion or a defect of the immature brain that interferes in the growth and in the child's maturation. Due to the difficulties of postural control and the maintenance of activities it is necessary to promote the inhibition of abnormal patterns of movements, to stimulate the existence of positions, to facilitate the accomplishment of some movements, looking for a better control of the same ones on the part of the child. Shepherd (1995) demonstrates the beneficial effects in the different ways and taking care of a child, since an acquired ability prepares the child to learn the next.

This study had as a main objective to investigate the activities of a child's daily life with cerebral paralysis according to the family, special school and regular school context. As specific objectives: to describe the child's main personal characteristic with cerebral paralysis in study; to characterize the contexts family, special school and regular school related the child with cerebral paralysis and the accomplishment of the activities of the daily life and to verify the relationships among the personal characteristic principal identified in the child with cerebral paralysis and the contexts characterized for accomplishment of the activities of the daily life.

PRESENTATION OF THE CASE

As the subject of the study a child was selected with cerebral paralysis, in preschool age (4 years), of the male gender that frequents the special school and the regular school in the city of Blumenau, in the year of 2004. The child does not have clinical diagnosis of chronic progressive encefalopatologia, living in the city of Blumenau, and was registered at the special school and at the regular school.

The parents authorized the accomplishment of the study with the child and they were also informed, as well as the teachers of the special school and the regular school.

The study was accomplished through the direct observation of the activities of the daily life accomplished by the child in the relative, special school and regular school contexts (in aleatory schedules during the period of one month, with medium duration of 50 minutes, twice a week), following the adapted from model of head office observation of Boroughs and collaborators (2001) adapted. An inventory of the child's life was accomplished based on the model of Tremea (2004) to verify the conditions from the birth of the child, problems of health, growth and development, living conditions, information of the activities of the daily life accomplished by the child and on his college degree. The Scale of Barthel (2004) was also used to evaluate the activities of the child's daily life. For better understanding of the investigated phenomenon it was used semi-structured interviews which were also accomplished, elaborated by the authors and validated, by the parents, teachers of the Special School and the Regular School.

ANALYSIS AND DISCUSSION

The obtained information were gathered, analyzed, interpreted and discussed as it proposes Triviños (1987), that suggests a triangulation of data of the reality observed with the information found in the literature and the researcher's perception.

The child was born for normal birth, with weight and stature inside the normality, however in the peri-native period present convulsion with cerebral anoxia, resulting in a chronic cerebral lesion, which took to serious espastic quadriplegia. The child's development was committed and according to the parents, the child began movement with about two years old, sitting down without front support, not developing for the other postures of the normal motor development. Very excited the parents made an observation, counting that he didn't know how to say if they had been happy or concerned with the fact that the child with approximately two years old it had fallen out of the double bed, by moving alone, concerned what the child's fall, but happy to see some type of the child's movement. Until the moment of the study the child had not also developed the verbal language, nor the

writing. For the punctuation obtained in the application of the scale of Barthel (2004), the child is totally considered dependent for the accomplishment of his activities.

Bobath and Bobath (1978) affirm that the child with cerebral paralysis grows in a slower rhythm and through an abnormal course. In serious cases the development can be completely sustained in soon in an initial learning, besides, while the alterations in the development of motors patterns of normal children to the fastest and significant until the five year-old the differences in a child's activities with cerebral paralysis are slower.

For Monhóz (2003) when accepting his son's condition the family becomes capable to create alternative solutions for the progress and the happiness, in the sense of transforming the pain and the suffering in love and pleasure. Stobäus (2003), tells that there are some difficulties with relationship to the child's acceptance who born different in a first moment, what cold moment of shock, where many times there are difficulties in the acting of papers, because besides learning to be mother or father, the children's with special needs parents will have to be a different child's parents, that they didn't expect, giving him a feeling of the healthy child loss, of the dreamed child. The parents have that individually and as couple, to feel secure and capable to recognize their confused feelings, to the new experiences that await them. For those reasons it is very important that the parents receive immediate support, so that they accept a new situation and with orientation they are lead in the best way.

The father still told that the pathology ended for strengthening even more the couple's union, and the respect, love, valorization of the attention, the need of affection was more visible among the couple. Bronfenbrenner (1996) considered that an atmosphere to be behaviorist is necessary to be exists in that place balance of power, reciprocity and affectivity among the people.

The child began the college degree in APAE with only 40 days and now also in the kinder garden. When they were questioned if the child liked to frequent the school, the parents said yes and they asked the question to the child, that through a communication system that developed with the parents, the own child tilted the body for the lateral, answering in an affirmative way. The same happened when it was asked if the child had a good relationship with your school friends and teachers, once again the own child answered yes.

Bailão and collaborators (2002), Souza and Ferrareto (1998), City and collaborators (2001) and Fonseca (1995) show that an intensive intervention in the first years of the child's life is essential for his development and it demands specific handling, accompanying the motive evolution preparing him for subsequent phases of his development. The parents believe, as well as all the professional interviewees, that the education process contributed a lot to the child's development, providing a larger cognitive, motor and mainly social development, besides stimulating his independence and autonomy, however they harmonized that it is necessary a larger preparation of the institutions for us to receive those children.

APAE possesses an educating proposal that has as larger objective the construction of a school that assumes a social commitment, given to the people inside with some need special pedagogic actions of an education perspective for life, believing that every body is entitled of learning, besides offering a therapeutic support to the child and his family.

During the observations accomplished in the special school and the application of the interview with the room teacher and the physical education teacher we noticed that professionals had a good affective relationship with the children, but at the same time firm during the requested activities, showing positive influences in the child's development. Bronfenbrenner (1996) shows that the good relationship among people in an environment influence the motivation for learning, could alter the course of the difficulties and accelerate the learning of the activities to be accomplished. The learning and the development are facilitated progressively by the child's participation in patterns more compounds of reciprocal activity with somebody to whom the child developed solid and durable emotional attachment, and when the balance of power returns to the child.

In the regular school the parents said that the child had a good acceptance for the direction, teachers and his friends. According to the parents' and of the own teachers of the school report in the beginning it was it a little complicated, because the teachers were not prepared to give him/her with that situation, but the "Alternativa" (public school that offers support to the enrolled special students' inclusion in the regular school) research, taking an extra teacher for the class room, to give a larger and more specialized attention to the child, besides, taking information and to guiding the other teachers remains with working with the child.

Several documents guarantee the right to education for the people with of special needs, such as the Declaration of Salamanca, LDB, Capitulate him/it III of the Federal Constitution, but in spite of that, in practice the schools they are not still prepared to receive those people yet. In Blumenau the exist service offered by the Alternative that gives support to the schools and the children's parents included in the regular school, but that is not reality in the whole country.

At home, as well as at school atmosphere the child needs aid to accomplish his tasks. Mancini and collaborators (2002) place that the difficulties in the acting of dialy activities life, are usually the children's, parents and family main complaint and that the promotion of the acting of those activities and functional tasks or able they shall be defined as objectives during the therapeutic intervention. In the cerebral paralysis, we can find deformities and patterns that hinder the postural control and the maintenance of reflex activities, so it is suitable the use of adapted materials and equipments that they favor the child's activities with a functional posture, stimulating the voluntary motor control, favoring the coordination optic-manual and the attention to the environment.

During the observations we verified that the child didn't possess any adapted material for feeding and hygiene at home and at schools, only some toys and his wheel chair, in the car the father also possesses a chair to transport the child. In both schools the teachers adapted some pedagogic materials, but they told, and it was also observed, that most of the time they worked helping the child through the passive movement, only in the physical education the teacher use materials that grabs the children's attention and they stimulate the curiosity. The teachers told they received information and the physiotherapist orientations of APAE on how to favor some movements, to stimulate postures, to inhibit patterns of movement reflex and to of aid during the accomplishment of some activities, however during almost all the observations the teachers supported the child in the accomplishment of his tasks through passive movement.

We also noticed that the other children always sought to help the special child in the accomplishment of the activities. At home the brother or the cousin (what was observed) to be tried always close to the child, trying to interact and helping in the accomplishment of some activity, as well as at schools, mainly in the regular school the other children showed plenty interest and motivation to help the child. Usually, there was dispute to see who would push the wheel chair, to sit down or to sleep close to the special child, besides the care in cleaning the sialorry with the diaper, to inform when he was crying, among other things. At home the parents told that the activities that the child accomplishes in your free time are usually activities that he demonstrates pleasure in accomplishing them, through the laughter, concentration, or even, through the form that the parents use to communicating with the child (the child places the body for one side, or, for the other answering in affirmative or negative way) usually in their company, or with grandmother. Among the activities that it accomplish is the parents mentioned: to play, to the mass, to watch television, to visit friends and family, among others.

The child with cerebral paralysis has many of his committed functions for the lesion, Mancini and collaborators (2002) place that it is in the functional limitation, in other words, during the acting of activities and tasks of the daily routine that the child's incapacity is manifested. For this reason is necessary that the professionals that work with that child, as well as the family, they should create evaluation strategies and intervention, looking for promoting the maximum of his independence.

CONSIDERATIONS

Due to our observation all the investigated contexts showed stimulants highly for the development of the activities of the daily life. The fact that the child with special need lives with the differences in different contexts, which was demonstrated as a facilitator for his development.

REFERENCES

- ATIVIDADES DA VIDA DIÁRIA. Escala de Barthel. Disponível em: <http://www.geocities.com/katerapiaocupacional/avdka.html> Acesso em: 28 jul. 2004.
- BAILÃO, M.; OLIVEIRA, J.; COBUCCI, P. **Educação Inclusiva**. Disponível em: <http://www.efdeportes.com/efd49/efi.htm> Acesso em: 17 ago. 2002.
- BOBATH B. **Desenvolvimento motor nos diferentes tipos de paralisia cerebral**. São Paulo: Manole, 1989. 123 p.
- BOBATH, B. **Atividade postural reflexa anormal causada por lesões cerebrais**. 2. ed. -Sao Paulo : Manole, 1978. 132 p.
- BRONFENBRENNER, U. A ecologia do desenvolvimento humano: **Experimentos naturais e planejados**. Porto Alegre: Artes Médicas, 1996. 267 p.
- BURGOS, M. S.; TREMEA, V. S.; KLINGER, H. I. **O Processo de Criatividade e Desenvolvimento Intelectivo na Dinâmica do Jogo Compartilhado**: um estudo com crianças de 5ª. série do Ensino Fundamental. Santa Cruz: UNISC, 2001. (Relatório de pesquisa PIBIC - CNPq).
- CIDADE, R. E.; TAVARES, M. C. G. C. F.; LEDEWIG, I. **Aprendizagem motora e cognição em portadores de deficiência**. Disponível em: <http://www.entreamigos/tema/esporte> (ultima atualização 5/12/2001).
- FONSECA, V. **Educação Especial**: programa de estimulação precoce (uma introdução às idéias de Fierstein). 2. ed. Porto Alegre: Artes Medicas, 1995. 245p.
- GALLAHUE, D. L.; OZMUN, J. C. **Compreendendo o Desenvolvimento Motor**: bebês, crianças, adolescentes e adultos. São Paulo: Phorte, 2001. 641 p.
- KREBS, R. J. Urie Bronfenbrenner e a Ecologia dos Desenvolvimento Humano. Santa Maria: Casa Editorial, 1995. 128 p.
- LEITE, G. **Qualidade de vida e saúde**. SECRETARIA DA EDUCAÇÃO, COORDENADORIA DE ESTUDOS E NORMAS PEDAGÓGICAS. O deficiente visual na classe comum. São Paulo: SE/CENP, 1993. Disponível em: <http://www.rumos.com.br/artigos/artigo007.asp> Acesso em 20 nov. 2004.
- LOPES, C. **A Criança Com Deficiência Física**. Disponível em: <http://www.bemnacido.com.br/df.html> Acesso em: 27 out. 2002.
- MANCINI, M. C.; FIUZA, P. M.; REBELO, J. M.; MAGALHÃES, L. C.; COELHO, Z. A. C.; PAIXÃO, M. L.; GONTIJO, A. P. B.; FONSECA, S. T. **Comparison of functional activity performance in normally developing children and children with cerebral palsy**. Arquivos de Neuro-Psiquiatria., Jun. 2002, vol.60, no.2B, p.446-452.
- MUNHÓZ, M. A. **A Contribuição de Famílias para as Possibilidades de Inclusão das Crianças com Síndrome de Down**: um estudo de caso. Porto Alegre, 2003. 188 p. (Tese de Doutorado em Educação da Universidade Federal do Rio Grande do Sul).
- OLIVEIRA, C. **A Escola Inclusiva**: A Criança Diferente / "Deficiente" face ao Sistema Educativo. Disponível em: <http://bve.cibec.inep.gov.br> acesso em: 27 out. 2002.
- PAULA, S. M. de. **Família e a Escola no Desenvolvimento das Atividades da Vida Diária: aspecto da reabilitação do deficiente visual**. UNICAMP - Universidade Estadual de Campinas. Disponível em: <http://www.icevi.org/publications/icevix/wshops/0031port.html>. Acesso em: 20 nov. 2004.
- SHEPHERD, R. B. **Fisioterapia em pediatria**. 3. ed. São Paulo: Santos, 1996. 421 p.
- SOUZA, A. M. C.; FERRARETO, I. **Paralisia cerebral**: aspectos práticos. São Paulo: Sarvier, 1998. 390 p.
- STOBÄUS, C. D. Criança com Necessidades educativas Especiais: Uma visão Ampla e Aportes Educacionais. In: KREBS, R.; COPETTI, F.; BELTRAME, T. S.; PINTO, R. **Os Processos Desenvolvimentistas na Infância**. Belém: GTR: 2003. 140 - 13 p.
- TREMEA, V. S. A inclusão de uma criança com Síndrome de Down na aula de educação física em uma escola particular no município de São José/SC. Florianópolis, 2004. 166 p. (Dissertação de Mestrado em Ciências do Movimento Humano da Universidade do Estado de Santa Catarina - UDESC).
- TRIVINOS, A. N. S. **Introdução à Pesquisa em Ciências Sociais**: a pesquisa qualitativa em educação. Augusto Nivaldo Silva - Sao Paulo: Atlas, 1987. 175 p.

Endereço: Rua Desembargador Pedro Silva, 2202, apt. 31 - bloco 9, Coqueiros
 CEP: 88080-700 / Florianópolis - SC / Brasil
 Telefone: 48-3348-2447 ou 48-8403-9445
 e-mail: fisioespecial@yahoo.com.br

ACTIVITIES OF THE DAILY LIFE OF A CHILD WITH CEREBRAL PARALYSIS IN THE FAMILY, SPECIAL SCHOOL AND REGULAR SCHOOL CONTEXTS (CASE REPORT)

ABSTRACT: The autonomy and independence of a child with cerebral paralysis can come committed due to some motor or cognitive deficit due to the pathology. Environmental events are capable to modify the child's evolution substantially, mainly during the first years of life, so the family and the school. Environments that role a fundamental part. The general objective of this descriptive study, about the report of case, with quali-quantitative analysis of the results, went to investigate the activities of a child's daily life with cerebral paralysis in the family, special school and regular school contexts. As subject of study a cerebral paralysis child was selected with, in preschool age, that frequented the special school and the regular school in the city of Blumenau. People that were part of those contexts also participated (parents, teachers of the special school and of the regular

school). The investigated contexts showed highly stimulants for the development of the activities of the daily life, however the activities need to be supported carefully, respecting the child's limitations, but always stimulating his maximum potential.

keywords: activities of the daily life, cerebral paralysis, contexts.

ACTIVITÉS DE LA VIE JOURNALIÈRE D'UN ENFANT AVEC PARALYSIE CÉRÉBRALE DANS LA FAMILLE, ÉCOLE SPÉCIALE ET HABITUÉ SCHOOL CONTEXTES (RAPPORT DU CAS)

RÉSUMÉ: L'autonomie et indépendance d'un enfant avec paralysie cérébrale peuvent venir s'engagé dû à quelque moteur du déficit, ou cognitif dû à la pathologie. Les événements de l'environnement sont capables modifier l'évolution de l'enfant substantiellement, principalement pendant les premières années de vie, pour que la famille et l'école, ils sont ambiants que joue une partie fondamentale. L'objectif général de cette étude descriptive, de l'étude du cas du type, avec analyse qualitative-quantitative des résultats, enquêter sur les activités de la vie journalière d'un enfant avec paralysie cérébrale dans la famille, école spéciale et contextes scolaires réguliers sont allés. Comme sujet d'étude un enfant a été sélectionné avec paralysie cérébrale, dans âge préscolaire qui a fréquenté l'école spéciale et l'école régulière dans la ville de Blumenau. Les gens qui faisaient aussi partie de ces contextes ont participé (parents, professeurs de l'école spéciale et de l'école régulière). Les contextes enquêtés sur si ils avaient montré des stimulants pour le développement des activités de la vie journalière hautement, cependant les activités ont besoin d'être servi de médiateur avec soin, en ce qui concerne les limitations de l'enfant, mais stimuler toujours votre capacité maximale.

Mots-clé: activités de la vie journalière, paralysie cérébrale, contextes.

ACTIVIDADES DE LA VIDA DIARIA DE UN NIÑO CON PARÁLISIS CEREBRAL EN LOS CONTEXTOS FAMILIA, ESCUELA ESPECIAL Y ESCOLARES REGULARES (INFORME DEL CASO)

RESUMÉN: La autonomía e independencia de un niño con parálisis cerebral pueden venir se presentar comprometida deuda a algún déficit motor, o cognoscitivo deudo a la patología. Los eventos ambientales son capaces de modificar la evolución del niño substancialmente, principalmente en los primeros años de la vida, para que la familia y la escuela, ellos son ambientes que tenne papel fundamental. El objetivo general de este estudio descriptivo, del tipo estudio de caso, con el análisis cuali-cuantitativo de los resultados, forra investigar las actividades de la vida diaria de un niño con la parálisis cerebral en la familia, escuela especial y contextos escolares regulares. Como sujeto de estudio se seleccionó un niño con parálisis cerebral, en edad del pré escuela que frecuentó la escuela especial y la escuela regular en la ciudad de Blumenau. También participaron las personas que estaban en los contextos (los padres, maestros de la escuela especial y de la escuela regular). Los contextos investigados si ellos mostraran los estimulantes favorablemente para el desarrollo de las actividades de la vida diaria, sin embargo las actividades necesitan ser mediadas cuidadosamente, mientras respetando las limitaciones del niño, pero siempre estimulando su potencial máximo.

Palabras clave: actividades de la vida diaria, parálisis cerebral, contextos.

ATIVIDADES DA VIDA DIÁRIA DE UMA CRIANÇA COM PARALISIA CEREBRAL NOS CONTEXTOS FAMILIAR, ESCOLA ESPECIAL E ESCOLA REGULAR (RELATO DE CASO)

RESUMO: A autonomia e independência de uma criança com paralisia cerebral podem se apresentar comprometidas devido a algum déficit motor, ou cognitivo decorrente da patologia. Eventos ambientais são capazes de modificar substancialmente a evolução da criança, principalmente durante os primeiros anos de vida, por isso a família e a escola, são ambientes que desempenham um papel fundamental. O objetivo geral deste estudo descritivo, do tipo estudo de caso, com análise quali-quantitativa dos resultados, foi investigar as atividades da vida diária de uma criança com paralisia cerebral nos contextos família, escola especial e escola regular. Como sujeito de estudo foi selecionado uma criança com paralisia cerebral, em idade pré-escolar, que freqüentava a escola especial e a escola regular na cidade de Blumenau. Também participaram as pessoas que faziam parte desses contextos (pais, professores da escola especial e da escola regular). Os contextos investigados se mostraram altamente estimulantes para o desenvolvimento das atividades da vida diária, porém as atividades precisam ser cuidadosamente mediadas, respeitando as limitações da criança, mas sempre estimulando seu potencial máximo.

Palavras chave: atividades da vida diária, paralisia cerebral, contextos.